Strong, generous support for medical research emerges from a large cohort of Swiss patients

Aguzzi, Adriano

DOI: https://doi.org/10.4414/smw.2017.14537

Established in 1871

Swiss Medical Weekly

Formerly: Schweizerische Medizinische Wochenschrift

An open access, online journal • www.smw.ch

Viewpoint | Published 22 October 2017 | doi:10.4414/smw.2017.14537
Cite this as: Swiss Med Wkly. 2017;147:w14537

Strong, generous support for medical research emerges from a large cohort of Swiss patients

Aguzzi Adriano

Institute of Neuropathology, University Hospital of Zurich, Switzerland; Editor in chief, Swiss Medical Weekly

When it comes to the attitude of the lay public towards medical science, the electronic media confront us with a frightening cacophony. Extremist views, grounded in ignorance and superstition, dominate the public discourse. The social media are particularly receptive to conspiracy theories, with the loudest (and wackiest) antiscientific voices capturing enormous attention. The consequences are often dire, as attested by the decline in vaccination rates and, consequently, by the resurgence of deadly infectious diseases thought to be long defeated.

If one goes by Facebook and Twitter, one might conclude that the majority regards whatever we scientists do as malevolent activities for the benefit of "Big Pharma" and to the detriment of mankind. But that is certainly not a representative measurement of the sentiment in the citizenry. In Switzerland, several referendums were held on laws directly affecting medical research, including the notorious "gene protection initiative" two decades ago, a popular vote on research with human stem cells, and ever-recurring attempts to introduce legislation banning animal research. All of these referendums elicited lively public discussion, and each one of them was won by supporters of medical science, indicating that a comfortable majority of the public wholeheartedly supports the advancement of medical progress.

Against this worrisome backdrop, it would be desirable to avail ourselves of direct, realistic measurements of the public's views of medical research. A touchy subject is research on human subjects that encompasses the sequencing of germ-line DNA. The study of Bochud and colleagues, now published in Swiss Medical Weekly [1], has addressed this question in a very straightforward manner using a large cohort of test persons. Over 25 000 hospital patients were asked whether they would consent to the use of their biomedical data and of their blood samples for medical research. It is truly heartwarming to learn that 79% of these persons consented to donating their data and body fluids to medical research. Even more interestingly, the consent rate was highest in the younger half of patients, suggesting that the young display a particularly generous attitude – a trend that may lead to even higher compliance in the future. What I found most surprising, however, is that a very impressive majority (93%) was willing to be recontacted for incidental findings requiring clinical action.

In summary, the message conveyed by the Bochud study is uplifting. Not only does a majority of the patients view medical research as worthwhile and desirable, but, when properly informed, they are willing to donate their data and (literally) their blood to research. The reality that emerges from this important survey could not be more different from what might be inferred from the internet's vociferous charlatans. The bulk of the citizenry (at least in a highly developed, wealthy country with a high educational level) sees medical research as an important and necessary endeavor. As we learned from this study, patients regard medical scientists as sufficiently dependable to be trusted with their most sensitive asset – their genetic and biochemical makeup.

Disclosure statement

Adriano Aguzzi is carrying out a population-wide screening project aimed at finding antibodies against relevant autoantigens in hospital cohorts.

Reference

1 Bochud M, Currat C, Chapatte C, Roth C, Mooser V. High participation rate among 25 721 patients with broad age range in a hospital-based research project involving whole genome sequencing – the Lausanne Institutional Biobank. Swiss Med Wkly. 2017;147:w14528. https://smw.ch/en/article/doi/smw.2017.14528/

Correspondence:
Prof. Adriano Aguzzi, MD, Institute of Neuropathology, University Hospital of Zürich, Schmelzbergstrasse 12, CH-8091 Zürich, Switzerland, Adriano.aguzzi[a]usz.ch